

***Delaware Health Resources Board  
Exceptional Care for Children 22-bed bridge unit  
Review Committee Meeting Minutes  
Wednesday, October 30, 2019 2:00 PM  
DelDOT Administration Building Farmington/Felton Room  
800 Bay Road Dover DE 19901***

***Review Committee Members Present:*** Theodore Becker Chair, Pamela Price and Edwin Barlow

***Staff Present:*** Latoya Wright and Elisabeth Scheneman

***Call to Order and Welcome***

The meeting of the Review Committee for Exceptional Care for Children (ECC) was called to order at 2:09 p.m.

***Review of ECC Certificate of Public Review (CPR) Application***

It was stated that the public notice for the ECC application was sent out on August 9, 2019. Representatives from ECC provided the HRB members a formal presentation outlining the details of the proposed project. The application has a 90-day review period. The HRB should vote on the project at the November 14<sup>th</sup> HRB meeting.

***Project Summary and Background Information***

Exceptional Care for Children (ECC) in Newark, Delaware provides long-term and short-term transitional skilled nursing care as well as palliative, and end-of-life care, for complex medical and technological dependent children. It is the goal of the organization to ensure that these children experience a true childhood, despite their medical limitations. ECC exists to help children for whom there are no other options. These are all children seeking a place to call home outside the confines of an acute care hospital. For these children, ECC offers a refuge and a home until they must transition from the ECC facility.

Transitioning individuals from pediatric to adult care is an issue of increasing concern, especially when it involves children with chronic conditions that are congenital and/or medically complex. The care of these children often requires the expertise of pediatric subspecialists in addition to actively involved primary care providers. When care of a medically complex or technological dependent child cannot be safely coordinated at home, and care in an acute care hospital is no longer warranted, ECC is a discharge destination that is safe, offers continuity of care, and is award winning for quality and standards of care. ECC serves as a home for these children until they reach adulthood, which is currently marked as their 21<sup>st</sup> birthday. Transition of a young adult patient from pediatric care to adult care is based on traditional age cutoffs instead of science.

Presently, 15 – 18% of children in the United States<sup>1</sup> have a chronic condition and among them, 98% will reach their 20<sup>th</sup> birthday. Further, 4% of those children are with medical complexity beyond their chronic condition as defined by 1) having one or more conditions with significant morbidity or mortality 2) functional limitations that significantly reduce their ability to perform

---

<sup>1</sup> Delaware Health and Social Services Medical Complex Committee (2018). *Identifying children with medical complexity*. Retrieved May 15, 2018 from <https://www.dhss.delaware.gov>

activities of daily living and 3) high healthcare needs that are invasive or require multiple disciplines to manage.<sup>1</sup> Healthcare transition for the “aging-out” child from ECC happens concurrently with other serious life changes and poses significant risk to the child as defined by the following:

- Termination of access to the school system including specialized therapies, socialization and augmentative services within the Department of Education
- Intricate physical and psychological developmental changes
- Loss of lifelong healthcare providers who understand their complete medical history
- Transition from a collaborative care model used in pediatric healthcare to a decentralized adult care model of care delivery
- A new expectation to navigate adult care models with a significant change in providers
- The difficult task of finding a team of adult healthcare providers with a comfort level to manage pediatric disorders
- Confusion, frustration and fear exhibited by both the child and parents/responsible parties regarding services available
- Affects to the continuity of care and coordination of services which increases the cost to the state of Delaware by way of increased visits, transportation, companion pay, potential in duplication of services, errors and omissions, and increased emergency room utilization
- Lapse in healthcare coverage, as payer change, which ultimately results in an undesired or negative outcome
- Inability of children to become primary medical decision makers, when self-advocacy is often an expectation in the adult care model
- Adult care settings are not equipped to manage patients with complex medical conditions that originated in childhood
- The lack of standardization for critical care pathways that affect this vulnerable population

The “Bridge Unit” construction scope includes new construction of a contiguous 2 story approximately 32,000 square foot structure that would include 22 private bedrooms, dining space, activities center as well as space to house all operational needs inclusive of clean/soiled utility, storage areas, nurse’s station and office space. Preliminary architectural design allows for shared services to the existing structure with satellite food preparation and storage, laundry facilities, electrical and mechanical housings and outdoor areas for residents. ECC will be required to build an outbuilding to hold liquid oxygen for medical gas connections to the resident headwall units and common spaces. These young adults are faced with barriers including lack of appropriate housing and home health staffing as well as reluctance from adult long-term care providers to accept admission due to complexity of needs. ECC respectfully request the opportunity to present their proposal to the Delaware Health Resources Board (HRB) in an effort to offer a plausible and solid solution to advance the healthcare needs of our most vulnerable population.

### ***Conformity of Project with Review Criteria***

The Review Committee reviewed the CPR application and the responses to the seven criteria.

Criterion I: The relationship of the proposal to the Health Resources Management Plan.

ECC has exhibited an exemplary record of accomplishment of managing children with medical complexities requiring long-term SNF care, transitional SNF care, palliative and end of life care services for those birth to 21 years of age. If found medically stable to meet pediatric SNF admission criteria, ECC is a significant cost savings to maintaining a child in an acute care center beyond their targeted date of discharge when a safe discharge to home not be feasible. ECC believe that they are best equipped to meet the needs of those residents who are aging out of their facility that need a lengthened stay due to lack of safe and appropriate discharge options in the community. ECC look to continually evolve their policies, procedures and programs to meet the needs of each individual resident and to adjust for new technology, new mandates, and the inevitable strides in modern medicine that accounts for the increase in need.

The Review Committee discussed the patient's temporary stay at ECC. A follow up question was sent to ECC requesting the definition of a temporary stay and how long does the patient stay if it is temporary. A follow up question was also sent to ECC inquiring if they are connected to the Delaware Health Information Network (DHIN).

The Review Committee agreed the application met criterion I.

Criterion II: The need of the population for the proposed project.

ECC seeks to meet the on-going complex medical healthcare needs of the children who have been diagnosed with chronic and progressive anomalies that will remain unresolved as they enter adulthood. Where their needs are ever-changing and will worsen with age, ECC look to prepare adult long-term care providers, and their affiliates, with a comprehensive and deliberate transition of care to best anticipate needs and prepare for positive outcomes, ECC seek to introduce and access the child's new adult care providers and payers prior to discharge to ensure appropriate, safe, timely, and cost effective care. When transition of care involves only an abrupt care transfer, pediatric patients may be put at risk associated with poor health outcomes, impairment, and high-cost emergency care.

Transition of care requires a significant amount of provider time, which can be a barrier to the benchmarks that determine success for a patient who is aging out of pediatric care. Pediatrics is a collaborative and coordinated centralized care model for those with complex medical needs whereas adult care is decentralized and self-advocacy driven. ECC provides complex medical care in a SNF environment to those that are age birth to 21 years old. ECC is looking to temporarily extend the stay of a child beyond 21 years of age in certain circumstances. ECC seek to introduce adult care providers prior to the residents impending discharge and to access their new adult care model providers and payers to ensure appropriate, safe, timely, and cost effective care. Delaware has identified areas of care needs for children with medical complexities and how to overcome those barriers through education, revision or current law, and engagement of payers and fixing the staffing/housing crisis.

The Review Committee agreed the application met criterion II.

Criterion III: The availability of less costly and/or more effective alternatives to the proposal of Delaware, including alternatives involving the use of resources located outside the State.

ECC has over the past 13 years of its existence, discharged 58 children to home. ECC have also discharged eight children to their partner providers upon the child reaching the age of 21 years old

and no longer qualifying for the pediatric health care SNF model. Feeling ill prepared to do so in this state due to the lack of resources in housing; grave staffing deficits from healthcare agencies; lack of pediatric knowledge by the adult care providers; and concerns related to the education/training potential for a caregiver. ECC states there are no current providers offering this level of service to ensure a safe, deliberate transition of care. Costs are driven by inappropriate discharge options without the ability to teach and train medical providers beyond ECC's level of care.

The Review Committee agreed the application met criterion III.

Criterion IV: The relationship of the proposal to the existing health care delivery system.

ECC is Delaware's only pediatric skilled nursing facility and its position in the community has been a cost savings to the State as well as its taxpayers since inception. While an actual reimbursement rate cannot be determined, assumption can be made that ECC is nearly 60-75% less than the daily billable rate with ancillary fee-for-service and bundling of an acute care facility for which ECC can safely admit, they are a fiscally responsible option. ECC operate to care for children who deserve the highest quality of care and services as well as to enhance their quality of life and to offer a childhood that each of them can tolerate on an individual basis. Since opening in February 2006 (and as of June 30, 2019), ECC has billed 119,488 patient days. ECC rate is all-inclusive with their average rate being \$1015.21 per resident day.

ECC's goal is to transition those children who will need ongoing SNF care into adult care with dignity, deliberate consultation, and a comprehensive plan of care which outlines the health history of each child. ECC will not accept admission requests for those over the age of 21yrs or those who have already accessed the adult care model.

ECC is quite accustomed to breaking new ground. Before ECC's inception, there was no option for those children who required extended stay subacute medical services in any other environment than acute care in the state of Delaware. The costs of acute care daily are 74% greater for the same level of care services when remaining in a hospital as opposed to a SNF. Now, as ECC children continue to age and outlive their prognosis, there is an identified gap of services for those turning 21 years old. They are required to access their care in the adult care model of services and payers. However, there is not sufficient time to prepare the accepting provider, let alone the child and their responsible party, for all the changes that are to come. ECC wants to bridge that gap.

The Review Committee discussed the transitioning process for patients. A follow up question was sent to ECC requesting the transition process for the children and at what point does the transition process begin.

The Review Committee agreed the application met criterion IV.

Criterion V: The immediate and long-term viability of the proposal in terms of the applicant's access to financial, management and other necessary resources.

ECC, through years of cost containment, effective negotiations with vendors, quality healthcare delivery without premature declines in health due to the caliber and integrity of its staff, shows a reduction in healthcare costs over the years in operation. The ability to maintain and grow operations with no increase to their daily rates since 2008, and with sound investments allows ECC

to report a healthy financial position. ECC intends to finance the project along with seeking grant opportunities by way of a fundraising campaign. The addition of the 22-bed unit will not realize an increase in Management or Administration costs but only minimal direct care, support staff, and ancillary staff. By maintaining centralized services, ECC anticipates Net Operating Income (NOI) to remain consistent with current outcomes. Upon completion, a reallocation of residents to the unit will be done, as there are currently 10 children who can move to this developmentally appropriate unit as adolescents, teens or young adult. Cost associated with the direct care needs of each child is anticipated to remain on target with current controllable expenses.

ECC also anticipate the increased costs to maintain an additional vehicle in their fleet to accommodate the children's needs for medical transport to routine and non-emergent appointments. ECC has been completing its own transports for the last 8+ years due to a self-directed Logisticare reimbursement agreement.

The Review Committee discussed Schedule 11 Sources of Financing. The Review Committee also discussed the bridge unit and reallocation of residents to the unit. A follow up question was sent to ECC inquiring on why adolescents are included in the transition to the bridge unit.

The Review Committee agreed the application met criterion V.

Criterion VI: The anticipated effect of the proposal on the costs of and charges of healthcare.

Financial Impact (first full year of operations)

Estimated effect on annual expenses:	Increase by\$ 4,307,469.00
Estimated effect on annual revenue:	Increase by \$ 4,038,001.00
Estimated effect on individual charges:	Decreased by 24,115.35 or \$1.22 per patient per day

The Review Committee reviewed the assumptions for the estimated effect on expenses, annual revenue and individual charges and also Schedule 4.

The Review Committee agreed the application met criterion VI.

Criterion VII: The anticipated effect of the proposal on the quality of health care.

As noted, ECC has a profound record of high quality care and services with award winning programs and has been the facilitator for designing a level of care for Delaware's most vulnerable citizens who would otherwise have required an extended stay if not their entire lives in an acute care setting. As Delaware's Advisory Committee to DHSS for Children with Medical Complexity hones in on the barriers in providing ECC children with prospects for on-going delivery of care systems as they age and enter adulthood, ECC feels that they can be part of the solution. Currently, even with discharge planning beginning on the day of admission, the chronic child is, on average, having their discharge plan and destination identified over no less than 4 years. ECC is certified by Medicare and Medicaid. ECC is accredited by the Joint Commission on the Accreditation of Healthcare Organization (JCAHO).

The Review Committee agreed the application met criterion VII.

Other Review Considerations

The project will offer economies and improvements in the delivery of service. The proposed Bridge Unit Project will first and foremost improve upon the quality of life of those children who require 24-hour skilled nursing care while in the pediatric care model who will undoubtedly qualify for and require continued skilled nursing facility services as they age out and enter the adult care model. The program will capture the necessary planning, development and execution of all providers to know the child, their plan of care, and ongoing health needs in the way of medical subspecialty requirements, impending procedures, equipment needs, and prognosis.

With no current provider in the community offering such a service as an alternative, ECC's intent is not to cause competition but to lay the ground work to help with the situation at hand. Continuous quality improvement is built into everything that ECC do. ECC choose to be a pioneer and a leader for their state, offering its most vulnerable constituents a pathway to safely transition from the pediatric care model to the adult care model by offering a short extension of the time that they can be the primary care providers instead of having everything change on the morning of their 21<sup>st</sup> birthday. ECC is Medicaid Certified and has admitted Medicaid payer children since it opened in 2006. When a payer source could not immediately be identified for a child that required admission and they did not need the services of an acute care hospital, ECC has accepted the resident, without question, even with the risk of non-payment.

The 22-bridge unit will also promote quality assurance and cost-effectiveness. The project will adhere to ADA requirements, employ energy principles and enhance the health care needs of the user population.

#### Recommendation

The Review Committee recommends approval of the CPR application submitted by ECC to construct a 22-bridge unit.

#### *Next Steps*

Staff will send the follow up questions to ECC for responses. The Review Committee will provide their recommendation of approval for the application to the Board at the November HRB meeting.

#### *Adjourn*

The meeting adjourned at 3:10 p.m.